
State of Rhode Island

Department of Human Services

Center for Child and Family Health

TECHNICAL RESOURCE DOCUMENTS

**Providers of Personal Assistance Services and Supports
(PASS)**

September 27, 2004

TABLE OF CONTENTS

Resource A:	Sample Assessment and Service Plan.....	1
Resource B:	Sample Assessment And Service Plan.....	18
Resource C:	Direct Service Worker Job Description Template and Contractual Agreement.....	35
Resource D:	Cueing	39
Resource E:	Ability to Accomplish/Perform Essential Activities of Daily Life and Age Appropriate Behaviors	40
Resource F:	Ability to Make Self-Preserving Decisions and Age Appropriate Behaviors	41
Resource G:	Ability to Make Self-Preserving Decisions and Age Appropriate Behaviors.....	42
Resource H:	CEDARR Family Center Provider Listing	43
Resource I:	Documentation Guidelines for PASS Services.....	44
Resource J:	Eligibility Criteria for PASS.....	47

RESOURCE A: SAMPLE ASSESSMENT AND SERVICE PLAN

Child: Margaret Smith (DOB – 3/20/96) – 8 years old

Diagnosis: Mental Retardation (unknown cause) – difficult to test, but IQ falls between 30 and 40 with many splinter skills, ADHD combined type, expressive and receptive language disorder.

Date of Plan: 7/10/04

PART A: ASSESSMENT OF FAMILY CIRCUMSTANCE AND PREPAREDNESS

I. Relationships:

- a) **Family** - Margaret lives in Cumberland with her mother, Marie; her father, Richard; sister, Jean (9); and brother, Jack (6). Extended family all live out of state, but Margaret accompanies family to visit relatives several times a year.
- b) **Friends** – Margaret knows many of her brothers' and sisters' neighborhood friends by name and they know her, especially Jesse, Justin, Chris (Jack's friends) and Lacey, Karen and Sarah (Jean's friends). These children frequent the Smith household and neighborhood play areas. Although never unkind, these acquaintances don't always seem to know how to include Margaret in their play. Margaret enjoys her classmates at Broad Street School. She knows children in her self-contained class, but also other typical grade level classmates from inclusion phys Ed, library class, music, art, and recess. She knows a few of the children in her Sunday school class at church.
- c) **Other Service Providers** – Margaret is in a self-contained special Ed classroom at Broad Street Elementary with inclusion classes as described above. She requires the assistance of a one-on-one aide at school to provide behavioral cues and redirection at a fairly high frequency throughout the day in all settings. She also receives speech therapy, OT and Adaptive Phys Ed. through school. The Smiths receive a few hours a month of respite service.

II. Personal Resources

What are Margaret's Strengths:

- Loves interacting with people – kids or adults (needs “interpreter” who understands her limited speech)
- Loves tennis or other net sports (watching TV or live, or participating as she can)
- Likes to “swim” (play in the pool)
- Likes baseball (watching), kickball (playing)
- Likes swinging
- Likes TV – Sesame Street, Tennis, favorite videos
- Likes letter identification games on the computer
- Does better when activities are structured

- Needs to keep physically active
- Likes music – hearing it, being around it (children’s choir at church)

What challenges Margaret?

- Great difficulty with motor planning and coordination
- Hates fine motor tasks (crafts, gluing, pasting, etc.)
- Most people do not understand her limited speech (needs “interpreter”)
- Certain loud noises (fireworks, babies crying) are aversive to Margaret
- Busy, chaotic, noisy environments can be overwhelming
- Margaret hates waiting and “down time” – sitting still
- Frustration can sometimes lead to aggression (pinching or hair-pulling)

III. Respect

Positive Qualities	Qualities often leading to rejection
<ul style="list-style-type: none"> • Cheerful, smiles all the time • Accepting of ALL others • Friendly • Wants to please • Concern for others • Energetic • Happy and joyful 	<ul style="list-style-type: none"> • Limited unintelligible speech • Repetitiveness in communication • Impulsivity – tends to interrupt, not wait for turn, walk in front of swings, cross street without looking, etc. • Short attention span (few seconds) • Occasional pinching or hair-pulling when frustrated • Lacks coordination for many childhood activities • Sucks on fingers, objects (other kids get grossed out)

IV. Choices

Made by Margaret	Made by others
<ul style="list-style-type: none"> • Food choices from array offered by family • Videotapes • Books to be read 	<ul style="list-style-type: none"> • Clothing to wear • Wake up and bed time • Menu offered • School activities • When to go out • Where to go when out • Who to stop and talk/play with

Margaret could be offered some structured choices about what she wants to do with non-TV leisure time, e.g. “would you rather find some kids to play tennis or go to the park for a swing?”

V. Home/Other environments

What Works?	What doesn't work?
<ul style="list-style-type: none">• Dedicated parents willing to do what it takes to care for Margaret• Parents dress, undress, bathe and toilet Margaret due to her coordination problems• Parents committed to including Margaret in all typical activities of the family, neighborhood and community.• Parents and sibs good at interpreting Margaret's speech• Caring sibs• Neighborhood kids are pleasant• TV keeps Margaret engaged and happy (tennis or favorite videos)• Food cut into small pieces – close monitoring for proper pacing during eating.	<ul style="list-style-type: none">• Parents are stretched between meeting Margaret's intense needs and needs of other sibs.• Attending "family" functions – scouts, school, church – parents need total focus on Margaret, can't participate in function• Margaret wants to engage with EVERY person, stranger or not (still rides in supermarket carriage to prevent this – soon too big)• Larger crowds are difficult• Other than TV, Margaret doesn't self-entertain constructively– needs constant supervision/engagement at all times• Unmonitored, Margaret will stuff during eating, swallowing food items whole (has needed Heimlich)

VI. Communication (Optional)

Communication is a major concern for Margaret

What works for Margaret?	What Doesn't Work for Margaret?
<ul style="list-style-type: none">• She wants to communicate• She is VERY persistent and creative in her attempts• Many of her words are intelligible• She uses gestures and signs to clarify her meaning• She will respond to "20 questions" when listeners are unsure what she means• Having a parent or sib to interpret for her to those not used to her speech• She has become familiar with computer keyboard and knows letters and their associated sounds	<ul style="list-style-type: none">• MANY of her words are unintelligible to those who don't know her well.• She can not string words together into sentences• When she cannot make her meaning understood, she whines repeatedly.• Often her inability to communicate results in frustration and aggression.

Margaret's school team feels she is a good candidate for an electronic communication device. They will be exploring various options during this school year.

VII. Health (Optional)

No unusual health concerns for Margaret

VIII. Daily Routine

7:30 AM – Mom or Dad waken Margaret and other children. One parent oversees sibs getting ready for school. Other parent takes Margaret to bathroom, dresses her, and brushes her teeth, hair.

8:00 AM –Margaret watches TV. One parent prepares simple breakfast. Other makes lunches. One parent writes note to Margaret's teacher. Other monitors Margaret's breakfast and gives meds. 8:10 special bus arrives for Margaret. Sibs go to corner for regular bus.

Parents quickly shower and off to work by 8:45 – Mom home from work at 3PM.

3:15 PM – Margaret's special bus arrives home from school. Mom greets her. Takes her to bathroom. Reads note from teacher. Margaret watches TV. Mom prepares a snack, monitors Margaret eating snack.

3:30 PM – Sibs arrive home from school. Get own snack. Relax for a few minutes. Go out to play. Margaret starts to whine. She wants to go out too.

4:00 PM – Mom takes Margaret out to walk around neighborhood. Find some kids playing ball at town garage (Jack is with them). Watch the kick ball game and participate for a while.

4:30 PM – Mom says time to go home and get dinner ready. Margaret balks, refuses to walk, attempts to bite Mom. Mom carries across street. Makes sure doors are closed tightly so Margaret doesn't go back out (Margaret can't turn door knobs). Once home in front of TV Margaret is happy. Mom can start dinner.

5:00 PM – Initial dinner preparations over. Mom takes Margaret to the bathroom, and then works with Margaret on homework (ten minutes or so). TV back on. Sibs come in from playing. Want something else on TV. Margaret whines. Sibs angry; go off to play computer upstairs.

5:30 PM – Dad home. Dinner. Dad cuts up Margaret's dinner and monitors intake. He eats his dinner after Margaret is finished (in 3 to 4 minutes or less – even monitored Margaret eats VERY fast). Margaret goes back to TV. Mom, Dad and sibs review day. Margaret intermittently comes back and attempts to grab food from other's plates.

6:00 PM – Mom takes Margaret to bathroom. Then Dad takes Margaret and Jack to town playground at Monastery. Mom and Jean clean up from dinner. Jean, who elected to stay home, starts on homework.

6:30 PM – Dad keeps close eye on Margaret so she doesn't run in front of swings; interprets her constant attempts to interact; keeps her from becoming annoying with repetitiveness or aggression with other children. Jack plays without a lot of adult interaction.

7:00 PM – Dad and kids come home. Mom bathes Margaret and dresses her for bed. Dad oversees Jack's homework.

7:30 PM – Margaret has her favorite "night snack," ice cream. Mom brushes her teeth. Reads her a story. Puts on her favorite CD to go to sleep. Asleep by 8PM.

8:00 PM – Dad oversees Jack's bath. Jack and Jean have some ice cream with Mom and Dad. (The Smith's have developed this routine of Margaret going to bed earlier even than Jack, her younger brother, so the two typical sibs have some time when Mom and Dad can focus on them without the distraction of constant supervision of Margaret).

8:30 PM – Jean takes her bath. Mom reads to Jack.

9:00 PM – Jack to bed. Mom reads to Jean.

9:30 PM - Jean to bed.

Analysis - The Smiths identified after school time as a time when extra supports are needed, especially to support Margaret in play activities that other children her age can do independently. They also feel that an extra pair of eyes and hands to monitor Margaret during dinner would free them up as parents to lead a more typical family dinner time, rather than focusing solely on Margaret during this time. Likewise, assistance with Margaret after dinner, but before bedtime would allow the Smiths to attend to the needs of all three of their children equally.

IX. What does Margaret need to learn about...

a) Activities of Daily Living

- When eating – take small bites, chew and swallow before next bite; use utensils, not hands
- Learn other safe ways to amuse self when at home besides TV (maybe books on tape, expand computer use??)
- Learn some independence in toileting.

b.) Safety and Self-Preserving Decisions

- Learn not to approach or greet strangers

- Distinguish between food and non-food items BEFORE she puts them in her mouth
- Practice safe street-crossing and playground safety with help

c.) Social Roles and Social Settings

- Make some friends among the neighborhood children
- Learn turn-taking in games with neighborhood children
- Learn better turn-taking in conversation (will need interpretation until [if] she learns communication system that unfamiliar listeners can understand)

X. What are Learning Opportunities in Margaret's Community?

a) What do her siblings do outside of school hours?

- They often play on nearby town garage grounds (parking lot and field) pickup games of kickball, four square, baseball, football, roller-skating, etc.
- Jean and Jack both play soccer in the fall with Cumberland Youth Soccer and baseball/softball in the spring with Boys and Girls Club.
- Jean is in the school chorus and band
- Jean is a Girl Scout; Jack a Cub Scout
- Jack occasionally goes with a friend to Boys and Girls Club after school drop in center or to swim.

b) What do other grade school age children do outside of school hours?

- Many children stay at B.F. Norton for the after school program there.
- Some children go to the Boys and Girls Club game room, gym and pool.
- Soccer and baseball are big with young kids in town
- Informal play, such as described above at the town garage

d) What Community Opportunities Match Margaret's interests, gifts, and capacities? What valued role or contribution would Margaret make in these settings?

1) Within walking distance?

- Informal games at town garage – Margaret could be included in kickball, four square
- Margaret could introduce rackets and balls to town garage parking lot activities for neighborhood pickup “tennis” games.
- Interaction with sibs and their friends when playing at home – board games, card games, tag, dress-ups, etc.
- High Street Market – with guidance, accompany sibs/friends on errands
- High Street Baseball field – watch little league games, learn to be a “spectator”
- Blackstone River Theatre – Musical performances for kids on Sundays – takes tickets?

2) Within five miles?

- Boys and Girls Club – Swim in the pool
- Girl Scout Troop - explore joining Jean's troop; meets Tuesdays 6:30 – 8PM
- Playgrounds – Monastery, B.F. Norton School, Ashton School
- Cumberland Library at Monastery – any musical programs for kids, computer activities?
- Siblings sports games (soccer, baseball, softball) – spectator role
- Tucker field – town tennis courts – spectator/ball girl?

PART B: GOALS/OBJECTIVES AND OUTCOMES IN PASS DOMAINS

I. Family's Priorities for Margaret in Home and Community

The Smiths feel that it is most important to give Margaret lots of opportunities to interact appropriately with other grade school age children so she can have the chance to form friendships. They would like the support of PASS during after school hours at home or in the informal play settings of the neighborhood (town garage and playgrounds) and also by having Margaret join the Girl Scout troop her sister attends. In these settings, Margaret can practice her communication skills, turn taking in conversation as well as cooperation in structured games and activities.

At mealtimes, Margaret needs almost constant “coaching” to moderate the pace of her food intake during meals. The Smiths would like help from PASS in this regard during dinner so the family meal can be a more relaxed experience for all family members.

The Smith's would also like PASS support to “coach” Margaret in alternatives to TV for self-amusement. This can be done on inclement days or after dark.

II. Goals and measurable objectives for the next six months

Domain A: (Activities of Daily Living) Margaret will begin to learn appropriate and safe pacing of eating her dinner, and begin to develop some independent leisure skills, and improve bathroom independence.

1. During dinner, with coaching, Margaret will learn to place her utensils on the table and take a sip of water between each bite she takes with 80% success.
2. When other children are not available to play with, Margaret will have mastered at least one activity she can engage in independently (as an alternative to TV). Perhaps books on tape, puzzles, matching cards, computer game, etc.
3. Margaret will tell her assistant when she needs to use the bathroom and will pull down her pants independently for toileting 100% of the time (up from 80%).

Domain B: (Safety and self-preserving decisions) Margaret will begin to learn and apply safety rules when out in the community (safe stranger behavior, safe street crossing and playground behavior)

1. In the course of neighborhood activities, Margaret will reduce the number of times she approaches or greets a stranger from an average of five per outing to two or less.
2. Margaret, with coaching every time, will begin to learn to STOP at the curb before crossing street and to STOP and move out in a wide arc before passing in front of swings.

Domain C: (Social roles and social settings) – Margaret’s amount and type of social interaction with neighborhood children and other social experiences will begin to more closely approximate that of a typical eight year old girl, giving her all the best chances to practice communication and social skills.

1. Margaret will increase the number of times she participates in neighborhood children’s games (kickball, four square, tag, etc. outdoors or board games, cards, dress-ups, etc. indoors) from one time a week to three or more.
2. Margaret will successfully recruit neighborhood children to play tennis so she can watch and/or play at least twice a month (she will provide them with rackets and balls).
3. Margaret will join her sister’s Girl Scout Troop and participate in the weekly meetings and other activities of the troop.
4. In the course of neighborhood play activities, Margaret will increase the amount of appropriate conversational turn taking from 20 – 30 % to 50% of the time.
5. In the course of neighborhood play activities, incidents of Margaret’s pinching or pulling hair will decrease from three a month to one a month or less.

Interface with other supports and programs

Many of these goals are mentioned in Margaret’s IEP. However, due to the nature of the academic setting, there often is not ample enough opportunity to practice these skills at school – e.g., eating, stranger behavior, street crossing, independent leisure activities, etc. The Smiths will pass on suggested strategies from Margaret’s Occupational Therapist, Speech/Language Consultant, and teacher. The opportunity PASS provides to practice these strategies frequently in naturally occurring settings in Margaret’s home and neighborhood will greatly enhance her improvement in these areas.

III. Relationship of PASS Goals to the expected role of parent/caregiver

The Smiths will continue to carry out all the expected roles and duties of parents of three school age children. In addition they will bathe and dress Margaret; closely monitor all of her eating except for weekday dinners when PASS support will do this; assist Margaret with homework assignments; follow routine to settle her for bed; interact with professionals in Margaret's life to learn best strategies to foster her success academically, behaviorally, socially, and communicatively; apply these strategies with Margaret themselves and pass them on to the PASS support worker; either Mrs. or Mr. Smith will check in on neighborhood activities Margaret is engaging in several times a week as they do their other children; they will offer volunteer support to the Girl Scout Troop to the same degree all parents are requested; they will interact with Troop leader on any specific planning that needs to happen to accommodate Margaret's disability. Additionally, the Smith's will be closely supervising the work of the PASS worker and providing ongoing training as Margaret's needs shift and change over time.

The role of the PASS support worker is to assist and/or coach Margaret in those roles, activities and/or interactions that most typical eight-year-olds can navigate independently without parental support. Without this support, the Smith's TOTAL attention needs to be on Margaret when she is at home and awake, sometimes to the neglect of their other two children. PASS Support is in no way planned to replace the role of parent in Margaret's life. In fact, it will allow the Smiths to be full parents to all three of their children.

PART C: INTENSITY, DURATION AND SERVICES SCHEDULE

Margaret's level of impulsivity requires almost constant direction and/or redirection unless she is watching TV. The Smiths feel pulled between this necessary supervision of Margaret and the appropriate level of attention to their other two children. They feel that weekends are doable with both parents home and everyone in a more relaxed mode. They also feel that they have developed a rushed, but workable weekday morning routine. The most difficult times are in the weekday afternoons when Margaret wants to be engaged with sibs or neighborhood kids and Mrs. Smith needs to attend to household chores and dinner preparation.

They also would like to be able to have a more relaxed family dinnertime. With someone supporting Margaret in pacing her food intake, the Smiths could attend to eating their own dinner and engaging all three children in dinner table conversation.

In examining community opportunities, the Smiths feel that enrolling Margaret in the Girl Scout Troop Jean attends would be another terrific opportunity to enhance Margaret's socialization and appropriate play. They would like PASS support during the meeting hours – Tues. 6:30 – 8PM – since it is not typical for parents to attend these meetings, yet Margaret will need support. The Smiths also would like to participate in Friday evening family swims at the Boys and Girls Club, but feel they would rather do that without extra assistance.

Therefore, the PASS Plan would allow for the following schedule:

Monday	4 – 7 PM	
Wednesday	4 – 7 PM	
Thursday	4 – 7 PM	
Tuesday	4 – 8 PM	
Friday	4 – 6 PM	Total 15 hours

The Smiths would like occasional flexibility to shift scheduled hours from afternoon to evening if there is an evening family event at school, scouts or church as these are difficult, but not regularly occurring, times when Margaret needs full assistance to participate appropriately and parents' focus may need to be on the other sibs. They understand that the total hours in any given week would not go over fifteen without a corresponding reduction in hours in a preceding or following week.

PART D: ROLES AND RESPONSIBILITIES IN DIRECT SERVICES

1) Activities:

1. After school neighborhood, playground, and/or indoor play activities
2. Girl Scouts Tuesdays 6:30 – 8PM
3. Dinner time
4. Independent leisure activities (not TV).
5. Occasional family events at school, scouts or church

a). Direct Service Worker Roles:

- Act as interpreter of Margaret's communication attempts with others (especially other neighborhood children)
- Act as a "coach" for Margaret in appropriate social behavior – turn taking in conversation and games, curbing impulsivity, etc.
- Act as a facilitator of Margaret's participation in activity at hand. This will be especially important at Girl Scouts because of variety of potential activities.
- Notice and report to Smiths all signs of blossoming friendships between Margaret and specific children so they might be fostered in other ways – invitations for play dates, etc.
- "Coach" Margaret in safe street crossing and playground safety. Also prompt her to curb her impulse to greet all strangers.
- "Coach" Margaret's proper pacing of food at mealtime – utensil down and drink of water between bites.
- There may be the occasional instance when PASS worker might need to drive Margaret to an event – e.g., library concert or other event that Margaret would enjoy but siblings wouldn't.
- Assist Smiths in monitoring and "coaching" Margaret at occasional family events.
- In partnership with Smiths, constantly look for other opportunities in the community for Margaret to engage with other children her age.

- Through daily checklist/log, record ongoing data related to the goals and objectives.
- Complete time sheets for signature by Smiths and submit to PASS Agency in timely fashion.
- Attend monthly meetings with Smiths and PASS Agency to monitor progress on the plan.

b). Margaret's Roles

- Desire to interact with others
- Strong desire to please
- Interest in sports, especially net sports and baseball/kickball
- Response to structure – Girl Scouts and games with “rules” are good settings for her

c.) Family's Roles

- Work on these goals with Margaret in other settings, especially on weekends
- Take Margaret and sibs to Family swim at Boys and Girls Club on Friday evenings.
- Make the appropriate inquiries/preparations with Girl Scouts and register Margaret
- Act as intermediary between school services/goals and goals of PASS, particularly around communication and behavior.
- Drive Jean, Margaret and PASS worker to and from Girl Scouts
- Recruit, train and supervise the PASS worker – especially in Margaret's “lingo.”
- Jean and Jack will frequently be available as in-home playmates for Margaret.
- Check time sheets for accuracy and sign
- Be available for monthly meetings with PASS Agency to monitor progress of PASS Goals

d). PASS Agency's Roles

- Hiring, training, and documenting processes
- Promote ongoing training seminars and educational opportunities for families and workers
- Ensure the continuity and quality of care and services through reporting and periodic evaluations as identified in the certification standards
- Provide prompt conflict resolution

d). Community's Roles (Potential)

- Cooperation of neighborhood kids
- Girl Scout Troop Cooperation
- Availability of Playgrounds, Library, Boys and Girls Club, Little League, etc.

PART E: IMPLEMENTATION STEPS AND TIMEFRAMES

I. Recruitment Plan

1. The Smiths have used three different respite workers who already know Margaret and her siblings. They plan to ask all three of these women if they would be interested in some or all of the PASS hours. Timeline – 9/17/04
2. If this does not result in filling all the necessary hours, they plan to post an advertisement through the special education department at school to all the special Ed teachers and teacher assistants. Timeline – 9/24/04
3. If the second strategy does not work, they will place an advertisement in the Valley Breeze (local newspaper) at the same time informing the PASS Agency of their difficulty in recruiting a worker. Timeline – 10/1/04
4. They will implement any suggested strategies provided by the PASS Agency. – 10/7/04.

II. Personnel activities

1. PASS Worker(s) will complete all required personnel paperwork no later than one week after agency agrees to hire, including:
 - ✓ Criminal background check
 - ✓ Driving Record check
 - ✓ W-4s and other tax documents
 - ✓ Employment eligibility verification
2. PASS Agency will process employee paperwork in a timely fashion

III. Training Plan

1. Once recruited and hired, PASS worker will participate in PASS Agency's required trainings (CPR, child development, etc.)
2. Mrs. Smith will provide the worker a list of the words Margaret says her own way with "translation."
3. Mrs. Smith will devote at least the first week on the job to accompanying Margaret and the worker to all the settings and activities they will frequent. Mrs. Smith will model and comment on the following, among other things:
 - "Interpreting" Margaret's unique combination of words, gestures and behaviors and what Margaret means by them to others (children especially, but adults also).

- Respectfully answering questions about Margaret raised by other children's curiosity.
 - Facilitating Margaret's participation in activities --- even if partial participation
 - Using positive behavior supports which work for Margaret
 - Explaining the limitations for Margaret created by her motor coordination difficulties and how to accommodate them
 - Demonstrate Margaret's bathroom routine and how to promote more independence.
 - Demonstrate the kind and amount of prompts necessary during eating to prevent choking.
4. The worker will have a chance to try these strategies and techniques while Mrs. Smith observes and gives feedback.
 5. The Smiths will train worker in how to collect and record daily data related to goals – simple checklist regarding what happened during shift.
 6. The Smiths will be available during most shifts for questions and clarifications.
 7. When Margaret's school team identifies further augmentative communication strategies or a device for Margaret, the worker will receive appropriate training along with the Smiths.
 8. The Smiths, PASS worker, and PASS Agency will participate in monthly meetings to assess progress, discuss any triumphs and/or challenges.

IV. Supervisory Roles of Family and PASS Agency

1). PASS Agency

- Assist family with recruitment strategies if initial recruitment efforts fail
- Assist PASS worker with required personnel paperwork
- Conduct background checks and process other paperwork in a timely fashion
- Assist family in setting up data collection checklist
- Provide training required for all PASS workers
- Pay worker based on submitted timesheets in timely fashion
- Attend monthly meeting with family and PASS worker to monitor progress on Plan
- Suggest strategies or further resources in areas that are showing little or no improvement
- Provide support to families, as requested, in supervision of worker

2). Family

- Take agreed on steps toward recruitment of worker
- Follow through on recruitment suggestions of PASS Agency

- Apprise PASS Agency Coordinator when worker is found and put them in contact with each other
- Train worker in Margaret's specific needs as outlined in training plan (above)
- Develop data collection checklist in collaboration with PASS Agency
- Check worker's timesheets for accuracy and sign for submission
- Provide ongoing supervision of worker
- Attend monthly meetings with PASS Agency Coordinator and Direct worker to monitor progress of plan.
- Apprise PASS Agency Coordinator of any unmanageable or unacceptable difficulties experienced with Direct Worker
- Inform PASS Agency Coordinator if Direct Worker resigns or gives notice of resignation
- Engage in timely re-recruitment efforts, should Direct Worker need to be replaced

PART F: SAFETY ARRANGEMENTS

For Margaret, her complex of disabilities creates several safety considerations:

1) Due to her impulsivity and problems with spatial body awareness it would not be unusual for her to run into the street or in front of a swing, etc. One of the PASS worker's roles will be to be vigilant to ensure that this does not happen, and to use every opportunity to coach Margaret not to engage in unsafe behaviors. 2) Unsupported, Margaret will approach everyone she sees whether familiar person or stranger. It would be very simple for someone with devious purposes to abduct her with Margaret's own full consent. Again, it is one of the responsibilities of the PASS worker to supervise Margaret's activities very closely to prevent this and furthermore to coach Margaret in distinguishing between acquaintances and strangers and the corresponding appropriate behavior.

2) Margaret can become aggressive when frustrated (her best method of communication of this feeling right now given her limited speech) – she will sometimes pinch and/or pull people's hair. This could be another child or the staff person. The Smiths will be training the PASS worker in how to prevent these occurrences as well as in appropriate consequences for Margaret should they occur, consistent with her positive behavior plan developed by the Smiths and Margaret's school team school.

3) Without monitoring, Margaret will stuff her food during eating sometimes to the point of blocking her airway. Preventing this, again, is one of the goals described above and a duty of the PASS worker to coach Margaret in proper pacing of food intake. Should an airway blockage occur during the family dinner, the Smiths would perform the Heimlich maneuver to dislodge the blockage. The PASS worker, having been trained in CPR, could also do this if either parent was not close at hand.

PART G: SIGNED CONTRACTUAL AGREEMENT

The purpose of this agreement is to clearly state the responsibilities of the family and PASS Agency to assure everyone understands these responsibilities.

Your responsibilities as a Family:

1. Verify family preparedness to effectively render consumer-directed PASS services.
2. Complete mandatory training provided by the PASS Agency.
3. Work with the PASS Agency to develop the Service Plan.
4. Designate a person who will be the responsible party for the family in decision-making activities with the PASS Agency and in managing the day-to-day work of the PASS worker(s). The designated family supervisor(s) is/are _____.
5. Find, interview and select the PASS worker(s). Submit the employment forms package(s) for the PASS worker(s) to the PASS Agency.
6. Train the PASS worker(s) about their job duties and what is expected of them.
7. Develop an emergency back-up plan for coverage when your regular PASS worker(s) is /are absent because of illness, transportation problems or needing time off.
8. Be certain that all hours worked by the PASS worker(s) are within the number of hours approved in the Service Plan.
9. Make sure that the PASS worker(s)' time sheet(s) reaches the PASS Agency on time which is every two weeks. You must complete the time sheet(s) weekly.
10. Review monthly budget reports of the hours worked and paid from the PASS Agency.
11. Assess and document child's progress toward Service Plan goals and objectives
12. Evaluate the PASS worker's performance in accordance with the Service Plan.
13. Contact your PASS Agency Coordinator when you have questions.
14. Contact your PASS Agency Coordinator if you have concerns, so small problems won't become big problems.
15. Maintain a safe and stable working environment in your home.

16. Follow proper reporting procedures (i.e. incidence reports).

Your PASS Agency's Responsibilities to you:

1. Ascertain family preparedness to effectively render consumer-directed PASS services.
2. Provide you with training about the PASS program and modify the training to meet your needs. This includes information about consumer-directed services, Medicaid requirements, recruiting, selecting and managing PASS Workers.
3. Collaborate with you in the development of the Service Plan.
4. Support you in the selection and management of PASS workers. Conduct Background Criminal Investigation (BCI) checks of PASS Workers.
5. Assure proper reporting of hours on timesheets & manage payroll for PASS workers.
6. Talk with you about your satisfaction regarding the quality of services you are receiving and assure that the PASS worker(s) activities are in accordance with the Service Plan.
7. Be available to you to answer questions or provide technical assistance in resolving problems or conflicts.
8. Work with you to develop a corrective action plan if there are difficulties managing your PASS worker(s).
9. Assure compliance with Federal and State employment laws. Monitor compliance with Medicaid Rules and Regulations.
10. Maintain a case record.
11. Assure proper reporting procedures, i.e. incidence reports.

What the PASS Agency will not do:

1. Interview, train or directly supervise your PASS worker(s).
2. Fill out the employment forms package.
3. Find emergency back up direct service workers for you.
4. Write your PASS Service Plan for you.

5. Approve additional hours beyond those authorized in the current Service Plan.
6. Provide your feedback to the PASS worker(s) regarding their job performance.

I understand, accept and agree to the responsibilities listed in this agreement and as delineated in the Service Plan

Family Supervisor(s) Signature

Date

Family Supervisor(s) Signature

Date

PASS Agency Coordinator Signature

Date

PASS Agency Clinical Coordinator

Date

* Adapted from "Consumers/Consultant Agreement", Consumers Directed Care Research Project, Florida Agency for Health Care Administration, December 1999

RESOURCE B: SAMPLE ASSESSMENT AND SERVICE PLAN #2

Child: Joseph Green (DOB – 3/20/88) – 16 years old

Diagnosis: Cerebral Palsy (athototic and ataxic wheelchair user), Mental Retardation (55 IQ), Profound Bilateral Hearing Loss (amplification in both ears), Absence Seizures, Auditory Hallucinations

Date of Plan: 7/10/04

Part A: ASSESSMENT OF FAMILY CIRCUMSTANCES AND PREPAREDNESS

I. Relationships:

a) Family - Joseph lives in Warwick with his mother, Sarah and his father, Charles. Joseph's grandmother lives in senior housing at the end of the street, about a half-mile away. The rest of the extended family lives out of state. Joseph's two older brothers are both out of state for college and medical school. Joseph accompanies his family to visit relatives several times a year. Grandmother lives in senior housing less than a half-mile away.

b) Friends – Joseph has friends that have known him a long time. One group are friends from church, most of whom live some distance from him so he gets to see them only weekly as he participates in church related activities. He is active in the church youth group and is included in all activities, even when they are held in places where wheel chair access is difficult. None of these church friends initiate contact or interact with him outside of church related activities. The other long-term friends come from a group of peers that he attended a special school with since age three. Since leaving there he has maintained contact by phone with one friend, John, on a regular basis and occasionally sees the others at special events only. Joseph arranges to see John at least once a year. Since he too uses a wheel chair it is difficult for them to get to any place independently. Joseph is well known by his peers at his high school since he attends only regular classes. He has managed to get the phone number of a few attractive girls and calls them occasionally. They are polite to him but do not speak to him for very long. He attends school activities when his parents can transport him. The school is barrier free and so Joseph attends there but his neighborhood peers attend Jefferson High School, which is within walking distance of Joseph's home. As a result he does not know any of the local teens.

c) Other Service Providers – Joseph is a freshman at Harding High School taking regular education classes. He requires the assistance of a one-on-one aide at school to help with personal care, to help him manage his materials, take notes for him, do any writing needed for him, to repeat critical information and to provide cues and redirection at a fairly high frequency throughout the day in all settings. He also receives speech therapy, Physical Therapy, Occupational Therapy and Adaptive Physical Education

through school. He is on the Home and Community-Based Waiver so he is provided with Certified Nursing Assistant (CNA) services for four hours, Monday-Friday, for personal care after school until his parents come home from work. During this time some CNA's who are able to, have helped him with his homework. Some have provided more limited assistance such as setting up and helping organize his homework assignments. His family is approved for 180 hours a year of respite. They routinely use less than 20 per year.

II. Personal Preferences:

What works for Joseph?

- Is very motivated by social interaction with children or adults (Is referred to as the 'Mayor' of Harding High School)
- Loves attending and watching girl's school sports events
- Loves sporting events with crowds, cheerleaders and lots of cheering; his favorite sport is baseball
- Loves movement and wheeling in his wheelchair
- Loves to ride in motor vehicles of any type
- Likes TV News and Weather
- Likes the outdoors including camping
- Likes to exercise on stationary bike and pretend that he is driving while looking at maps
- Likes soft rock music especially Neil Diamond

What doesn't work for Joseph?

- Great difficulty with coordination
- Hates fine motor tasks
- Strangers do not understand his speech (needs "interpreter")
- Busy, chaotic, noisy environments can be very distracting

III. Respect

Positive Qualities	Qualities often leading to rejection
<ul style="list-style-type: none"> • Positive attitude and pleasant demeanor (Don't worry be happy) • Accepts all people and seeks to interact with them • Self confident and willing to try new things • Wants to please and be accepted • Concern for feelings of others • Energetic and physically strong • Loves to stay very aware of current events • Uses computer for written output 	<ul style="list-style-type: none"> • Strangers have some difficulty understanding his speech • Tends to interrupt conversation, not wait for turn • Touches to get attention • Flirts with females and asks for hugs and kisses • Limited coordination for most activities • Loud voice with difficulty hearing low volume speech

IV. Choices

Made by Joseph	Made by others
<ul style="list-style-type: none">• What to eat and wear from options offered by parents• What to do with free time:<ul style="list-style-type: none">TV/RadioPhone friendsRead books or mapsWheel* in neighborhoodAttend social/sports events• Friends and associates	<ul style="list-style-type: none">• Sleep schedule controlled by family routines• School related activities• How to get to where he wants to go• Accessibility limits choices• Family activities and events

*Travel by Wheelchair

Joseph's choices are limited by his need to be transported everywhere except around his neighborhood. He is able to wheel considerable distances from his house by himself.

V. Home/Other environments

What works?	What doesn't work?
<ul style="list-style-type: none">• Dedicated parents willing to do what it takes to care for Joseph• Parents bathe and help Joseph finish dressing due to coordination problems• Parents committed to including Joseph in all typical activities of the family, neighborhood and community.• Parents good at interpreting Joseph's speech and needs• Lots of acquaintances• Joseph is happy to amuse himself with his interests• Food needs to be cut into small pieces but can feed self.	<ul style="list-style-type: none">• Parents are stretched between meeting Joseph's needs and employment and volunteer responsibilities.• When attending functions one parent needs to focus on Joseph, thus can't participate in function• Flirting/touching behavior may make some girls/women uncomfortable and reluctant to interact with Joseph• Larger crowds are difficult to maneuver in a wheelchair• Friendships are superficial and one way• Many community activities are held in inaccessible locations• Sidewalks are either nonexistent or do not have curb cuts, so Joseph is often wheeling in the street

VI. Communication (Optional)

Social interaction is very necessary for Joseph

What works for Joseph?	What Doesn't Work for Joseph?
<ul style="list-style-type: none">• He wants to communicate and seeks out opportunities to meet others• He is VERY persistent and creative in his attempts• He is easily understood by those who have been around him for a while• He will use alternative words or spell words when someone tells him they don't understand• He will write words that are still not clearly understood• Having a parent to interpret for him to those not used to his speech	<ul style="list-style-type: none">• Some who don't know him well lose interest in communicating• Some who don't know him well don't tell him that they can't understand• He touches people to get their attention; because he is sitting in his wheelchair, those areas that are touched are parts of the body that most people are not comfortable having touched

VII. Health issues that impact community participation (Optional)

Do not limit community activity	Barriers to community activity
<ul style="list-style-type: none">• Good upper and lower body strength• Can maneuver wheelchair in all environments• Can negotiate most surfaces independently• Can transfer from wheelchair• Can "walk" when provided support and balance by others	<ul style="list-style-type: none">• When absence seizures are occurring he appears to just not paying attention<ul style="list-style-type: none">• Lethargic and cold after seizures• Requires physical assistance to deal with non-accessible locals• Accessibility limits choices

VIII. Daily Routines

5:00 AM – Dad wakes Joseph who does not respond to an alarm when his hearing aids are out. He assists with bathing, dressing, shaving, teeth brushing, hair combing and gathering school materials.

6:15 AM – Breakfast, usually takes 30 minutes for Joseph to eat a bowl of cereal by himself.

7:15 AM – School bus picks up Joseph

2:15 PM – Joseph's special bus arrives home from school. CNA greets bus and brings him in where she helps him take his coat off and takes him to the bathroom. CNA prepares a snack, monitors Joseph's eating. When CNA is not available, mother comes home from work early. When this is not possible a neighbor meets the bus and gets Joseph into the house and waits until one of his parents arrives to help with bathroom, etc.

3:00 PM – Homework time. CNA lays out the work, reads the instructions and helps when s/he is able to do the work. (Some CNA's have not been able to help with homework.)

5:30 PM – Mom and Dad home.

6:00 PM – CNA leaves after helping with bathroom routine. Joseph watches TV News until dinner.

6:30 PM – Family dinner with NBC National News on TV in the kitchen.

7:30 PM – More homework with Dad's assistance when he is home or with Mom. If no homework Joseph has free time for reading, exercising, radio/TV, phone calls, etc.

8:30 PM – Preparation for bed started. Bathroom routine, changing, setting VCR to record 11:00 PM news on NBC, hearing aids out and into bed around 9:30 PM and asleep within minutes!

Analysis: The Greens are currently using CNA services to provide care and support to Joseph at home after school. This support allows them to both work and thus is a significant help. However, this support is keeping Joseph confined to his home. Beyond the personal care, some limited assistance with homework, and some limited homemaker type support the CNA service is not helping the family advance Joseph's move toward independence. They are seeking to replace the 20 hours per week of CNA service with an equal number of hours of support that will bring Joseph into this community and which will teach him community use, survival, and membership skills.

IX. What does Joseph need to learn about...

a) Activities of Daily Living

- Learn where all of the different stores, food places and recreation sites are within wheeling range of home
- Learn how to use the bus to get to various community places such as library, mall, entertainment
- Learn how to independently use public bathrooms
- Learn to get into house, make own snacks and use the bathroom without assistance

b) Safety and Self-Preserving Decisions

- Learn not to touch females for their attention
- Learn to interact with females in ways that does not involve hugging and kissing of girls and women that do not want this level of contact
- Learn to use a cell phone to get help and information when lost

c) Social Roles and Social Settings

- Get to know teens in neighborhood
- Learn turn-taking and avoiding interruptions in conversations
- Attend school sports events and school dances
- Experience the work environment

X. What are the Learning Opportunities in Joseph's Community?

a) What are his siblings doing outside of school hours? N/A

b) What do other teens do outside of school hours?

- Many participate in school clubs and sports
- Some go to work
- Some hang out at friends or at local hangouts
- Most are not doing their homework as soon as they get home

**c) What Community Opportunities Match Joseph's interests, gifts, and capacities?
What valued role or contribution would Joseph make in these settings?**

1) Within walking distance?

- Jefferson High School - Joseph could:
 - ✓ Watch sports practices and encourage athletes
 - ✓ Do laps around tennis courts or track when not in use
- Cosmic Pizza - Joseph could
 - ✓ Learn to make purchases
 - ✓ Explore work opportunities
 - ✓ Get a meal when parents are late from work
- Fantastic Sam's – Joseph could:
 - ✓ Get own hair cut
 - ✓ Explore work opportunities
- Three RIPTA bus stops for three different fixed routes – Joseph could
 - ✓ Escort grandmother on bus trips
 - ✓ Learn the three bus routes
- Brook's Drugs – Joseph could
 - ✓ Pick up his own medications
 - ✓ Take his film to be developed and get pictures back
- Community Credit Union – Joseph could

- ✓ Open an account
- ✓ Learn about money management

2) Within five miles?

- Malls and shopping centers – shopping, hanging out, work opportunities
- Public library – leisure reading, work
- Grocery stores – food shopping, work
- Movies, museum, theater – leisure activities by self or with friends
- Church - activities

d) What valued role or contribution would Joseph make in these settings?

- Offer friendship and hospitality to peers and others in need of more contact with their community
- Perform needed work
- Change perceptions and opinions of community members about others like himself
- Help others become more comfortable and confident in their role as natural supporters

PART B: GOALS/OBJECTIVES AND OUTCOMES IN PASS DOMAINS

I. Family's Priorities for Joseph in Home and Community

The Greens feel that it is most important to prepare Joseph to live more independently without the need for constant support, both at home and in the community. He is getting old enough to be taking on more responsibility for himself. They have recognized that they or others are always having to be with him and do things for him. They wonder how much he could do for himself. They would like to use PASS to advance his independence by trying to give him skills that will make him less dependent on others, to become more independent in familiar settings in the community, and to become more socially competent. They would like to use natural settings that Joseph is or should become familiar with to build real life skills.

They believe that he needs to become more able to care for his personal grooming and toileting needs so that if he were in a situation where a PCA is not available he could care for himself and thus stay in those natural settings. This is particularly important in terms of toileting in community environments where his current home semi-independent toileting strategies cannot be used.

Some of Joseph's interpersonal communication and interaction skills like touching and flirting with females are a concern because they might lead to rejection or worse. He needs to learn how to get people's attention appropriately, how conversation is structured as a back and forth exchange, and what is appropriate conversation with strangers and casual acquaintances.

Finally they want Joseph to spend less time at home and more time in the community without their direct involvement and presence. Being very aware of Joseph's current levels of functioning in these priority areas, they have identified specific goals that they believe attainable within the next six months.

II. Goals and measurable objectives for the next six months

Domain A (Activities of daily living) – Joseph will learn new skills that will allow him to take care of some personal needs at home and in the community and thus be more able to venture into community settings without an adult to assist him.

1. Joseph will learn to let himself into his house after school and take care of his bathroom needs independently by the end of six months. He will wash his hands after coming in from outside, after toilet use and before meals 75% of the time without cueing.
2. When in community settings he will learn to find accessible public rest rooms in restaurants, grocery stores and public buildings, 100% of the time; become familiar with their layouts and practice independent transfer and toileting maneuvers daily when in community settings.
3. He will learn locations of the different places where he can buy food (prepared or for preparation at home) that he can reach by wheeling.
4. Joseph will learn the location of all of the different bus stops in his neighborhood and ride the RIPTA fixed route busses.

Domain B (Safety and self preserving decisions) – Joseph will more actively participate in his health care and will learn about personal safety in community settings.

1. Joseph will wheel to the local pharmacy at least once a month to pick up his medications as prescriptions are filled or refilled.
2. While on community outings, Joseph will call his parents using his cell phone to describe where he is and what he is doing, leaving that information on the answering machine if there is no one to answer the phone at home.

Interface with other existing supports and programs

Joseph, although fully included in Harding High School, still receives special education services. He has a transition plan that addresses many of the same goals as his PASS Service Plan. The educational goals, the SPL, OT and PT services are provided by appropriately licensed or certified professionals. These individuals can provide professional advice and instruction to Joseph as well as his parents. This information and instruction can be transferred to PASS workers for practice and application in real life settings, something that is difficult to do in a school setting. The school-based

professionals can help assess the progress of skill acquisition and objectively measure changes and progress toward goals.

DOMAIN C (Social roles in natural settings) - Joseph will increase the amount of time he spends in neighborhood settings where he will have a chance to interact with typical peers or be able to explore work opportunities

1. Joseph will explore his community that is within his wheeling range and explore by entering three new sites per week. He will create a personal map of at least 20 places visited that are of interest to him. He will add 10 additional places where he might find work opportunities and where his PASS worker and parents think he can find opportunities to interact with community members and peers.
2. Joseph will learn to introduce himself to at least 25 community members he meets in these settings by identifying himself as someone living in the neighborhood, inquiring if the person lives close by, saying that he hopes that they will meet again and saying good-bye. He will create a personal list with the names of all the peers that he has met in this process.
3. Explore the possibility of Joseph functioning as a greeter in some of the business sites that he is interested in as a way of improving communication skills. By six months he will be functioning as a greeter in at least one location.
4. Joseph will attend at least two out of school events per month where there are large numbers of Harding HS students where he will practice appropriate social exchanges that involve occurrences of common interest or experience. He will choose these events from a school event calendar

III. Relationship of PASS goals to expected role of parent/caregiver

The three critical parental responsibilities of assuring the health and safety of Joseph, planning and orchestrating Joseph's community experiences, and the shaping of his character and citizenship role are the responsibility of his parents. Sixteen-year-old boys without disabilities function almost completely independently of direct hands-on parental support in all three PASS priority areas. Joseph cannot do this. He requires additional teaching, support and direct assistance. This level of support is far beyond the usual and customary roles played by parents of typical sixteen year olds. Sixteen-year-old boys without disabilities are appropriately socially and emotionally distancing themselves from parents. When parental involvement continues at the level of intensity needed by Joseph, family relations are strained and the movement toward independence is retarded or stopped. Given the goal of increased autonomy and reduced reliance on family and others, reducing direct family participation in this process is necessary.

These supports are needed because of disability-produced barriers to normal living, safety, and community membership. Without this support Joseph's future quality of life will be greatly compromised. The goal of this PASS Service Plan is to provide him with

the best reasonable opportunity to become a contributing member of the community. A collateral family-centered goal is to make sure that his parents' ability to continue in their contribution and productivity is not compromised.

PART C: INTENSITY, DURATION AND SERVICE SCHEDULE

Previous assessments have identified that given the family circumstances and Joseph's constellation of needs, he is eligible for 20 hours per week of CNA services and 180 hours per year of respite for the parents, provided through the MR/DD Waiver.

Joseph's daily schedule includes school daily even through the summer. His availability for community-based learning and development is limited to the period immediately after school until dinnertime. After that his time needs to be devoted to family time, schoolwork, and preparation for the next day. The goals and objectives are easily worked on during this time frame since this is the time when there is an increased probability that Joseph may interact with peers.

Given the need to physically explore his environment close to home, transport time to and from various sites will need to be included in any excursion. When exploration reaches out beyond wheeling range the time devoted to travel will become even greater. A collateral benefit of this wheeling will be Joseph's increased endurance and stamina. This may prepare him for exploring the possibility of future participation in some form of athletic event such as wheelchair racing.

Schedule: Monday through Friday 2-6 PM **Total 20 hours**

The Greens would like the occasional flexibility to shift scheduled hours from afternoon to evening if there is an evening event at school or in the community. More rarely an occasional Saturday football game attendance may require some support and the shifting of the schedule. This is particularly desirable during school events where the presence of parents is not appropriate.

PART D: ROLES AND RESPONSIBILITIES IN DIRECT SERVICES

a) Joseph's Strengths in Support of Goals

- Strong desire to interact and communicate with others
- Loves to wheel and move in all settings
- Enjoys school sports and social events
- Strong interest in the world around him
- Motivated by the desire to be around women and to meet them

b) Family's Role in Support of Goals

- Work on these goals with Joseph in all settings, especially on weekends
- Arrange for a reduced homework load by requesting more time to do homework in school

- Get a cell phone and bus pass for Joseph
- Provide him an opportunity to earn some money for his community purchases
- Provide a weekly shopping list and at least one time a week to eat out
- Recruit, train and supervise the PASS worker
- Sign time sheets and submit to the PASS Agency
- Be available for monthly meetings with PASS Agency to monitor progress of PASS Goals

b) Community's Role in Support of Goals

c)

- Recognition of Joseph as an individual with a unique personality
- Cooperation and openness of neighbors and local business operators
- Acceptance of and comfort with Joseph by school peers

d) Role of PASS Worker in Support of Goals

- 1) Activities:** After school neighborhood and community exploration
 Social interaction coaching, cueing and support
 Asking and inviting community members to get to know Joseph
 Teaching independent bathroom use skills
 Transporting Joseph to activities not conveniently reachable by walking or bus

2) Direct support responsibilities:

- a. Act as mediator of Joseph's communication attempts with others
- b. Act as a "coach" for Joseph in appropriate social behavior – turn taking in conversation, curbing impulsivity, etc.
- c. Act as a facilitator of Joseph's participation in community activities.
- d. Notice and report to parents all signs of blossoming friendships between Joseph and specific peers and neighbors so they might be fostered in other ways
- e. "Coach" Joseph in bathroom use at home and in the community
- f. Teach Joseph how to access and use RIPTA buses
- g. Teach community utilization skills including: shopping money use, situational awareness, etc
- h. Facilitate Joseph's active participation in after school events where he can interact with school peers

- i. In partnership with the Greens, constantly look for other opportunities in the community for Joseph to engage with other teens in the community.

PART E: IMPLEMENTATION STEPS AND TIMEFRAMES

I. Recruitment Plan

1. Joseph has had a few school aides he has particularly liked and who have enjoyed working with him. The Greens plan to ask all three of these women if they would be interested in some or all of the PASS hours. Timeline – 10/17/04
2. They also plan to ask the neighbor who occasionally helps Joseph off the bus when the CNA was not available. Timeline – 10/24/04
3. There are a few church members who are very comfortable with Joseph and who have taken an interest in him as teachers or friends. Some of the youth who are a few years older than Joseph but still in the area going to college may be interested in getting paid to help Joseph be a regular guy. Timeline – 11/1/04
4. Joseph's favorite cousin is coming to Providence College; she may be interested in making some extra money as a PASS worker for him. Timeline – 11/7/04

II. Personnel activities

a) PASS Worker(s) will complete all required personnel paperwork no later than one week after selection by family, including:

- ✓ Criminal background check
- ✓ Driving Record check
- ✓ W-4s and other tax documents
- ✓ Employment eligibility verification

b) PASS Agency will process employee paperwork in a timely fashion

III. Training Plan

1. Once recruited, PASS worker will participate in PASS Agency's required trainings (CPR, child development, etc.)
2. Mr. Green will teach worker how to disassemble and assemble the wheelchair and how to assure that hearing aids are set for optimal amplification
3. The Greens will devote at least the first week on the job to accompanying Joseph and the worker into some of the settings and activities they will frequent. They will model and comment on the following, among other things:

- Meeting community members and explaining the purpose of their presence if a goal is to support interaction between Joseph and others in that environment
 - Respectfully answering questions about Joseph raised by others' curiosity.
 - Facilitating Joseph's participation in activities --- even if partial participation
 - Explaining the limitations for Joseph created by his motor coordination and hearing difficulties and how to accommodate them
 - Demonstrate Joseph's bathroom routine and how to promote more independence
 - How to recognize Joseph's seizures and how to respond to them without alarming Joseph and others in the area
4. The worker will have a chance to try these strategies and techniques while the Greens observe and give feedback.
5. The Greens will be available by phone during most shifts for questions and clarifications.
6. The worker will learn to check with Joseph about his preferences for activities, when and where to go, what kinds of work experiences he would like to try, what school events he wants to attend, etc.
7. The Greens, PASS worker, and PASS Agency will participate in monthly meetings to assess progress, discuss any triumphs and/or challenges

IV. Supervisory Roles of Family and PASS Agency

a) PASS Agency

- Assist family with recruitment strategies if initial recruitment efforts fail
- Assist PASS worker with required personnel paperwork
- Process background checks and other paperwork in timely fashion
- Assist family in setting up data collection checklist
- Provide training required by all PASS workers
- Pay worker based on submitted timesheets in timely fashion
- Attend monthly meeting with family and PASS worker to monitor progress on Plan
- Suggest strategies or further resources in areas that are showing little or no improvement
- Assist family, as requested, with any difficulties of supervision or management of worker

b) Family

- Take agreed on steps toward recruitment of worker
- Follow through on recruitment suggestions of PASS Agency
- Apprise PASS Agency when worker is found and put them in contact with each other

- Train worker in Joseph's specific needs as outlined in training plan (above)
- Develop data collection checklist in collaboration with PASS Agency
- Check worker's timesheets for accuracy and sign for submission
- Provide ongoing supervision of worker
- Attend monthly meetings with PASS Agency and worker to monitor progress of plan.
- Apprise PASS Agency of any unmanageable or unacceptable difficulties experienced with worker
- Apprise PASS Agency if worker resigns or gives notice of resignation
- Engage in timely re-recruitment efforts, should worker need to be replaced

PART F: SAFETY CONSIDERATIONS

For Joseph, his complex of disabilities creates several safety considerations:

1) As a hearing aide wearer Joseph can usually hear well in all environments. If one or both of his aids malfunction his hearing is greatly compromised. Besides causing communication problems he may not be able to hear ambient noises that alert him to the approach of a vehicle from behind for example. He is aware when the aids are not working well. He will usually alert someone about this. However the PASS worker will still need to assure that the aids are working by asking Joseph before they leave the house and take the necessary corrective action, replace a battery, clean the aid, etc.

2) Joseph has an extremely high threshold for pain. Occasionally when wheeling down ramps and other inclines with walls or railings he has smashed his hands against these objects. This has resulted in broken fingers and sprains as well as lacerations and abrasions. He has ignored them and continued on his way. When someone notices his injury he will say something like, "I must have hurt it," but not complain. PASS workers need to assess any such injury as soon as they become aware of it and respond with the appropriate first aid if needed.

3) Although his absence seizure activity is well controlled by medication that is administered by his parents daily, Joseph will still have an occasional seizure (one or two per year). Their onset is unpredictable and for most people they are even unobserved. During an absence seizure he will stop talking and stare into the void. This will last a second or two and then he will become alert again but not aware that anything had happened. He will report that he is tired and be lethargic for an hour or two. He will then revert to his normal routine with no apparent effect. The seizure is most easily recognized as having occurred during the post seizure period. If this rare event should occur the PASS worker should remain calm, give Joseph a chance to recoup and rest if needed and then help him to return to the activity at hand as soon as he reports that he is ready.

PART G: SIGNED CONTRACTUAL AGREEMENT*

The purpose of this agreement is to clearly state the responsibilities of the family and PASS Agency to assure everyone understands these responsibilities.

Your responsibilities as a Family:

1. Verify family preparedness to effectively render consumer-directed PASS services.
2. Complete mandatory training provided by the PASS Agency.
3. Work with the PASS Agency to develop the Service Plan.
4. Designate a person who will be the responsible party for the family in decision-making activities with the PASS Agency and in managing the day-to-day work of the PASS worker(s). The designated family supervisor(s) is/are _____.
5. Find, interview and select PASS worker(s). Submit the employment forms package(s) for the PASS worker(s) to the PASS Agency.
6. Train the PASS worker(s) about their job duties and what is expected of them.
7. Develop an emergency back-up plan for coverage when your regular PASS worker(s) is /are absent because of illness, transportation problems or needing time off.
8. Be certain that all hours worked by the PASS worker(s) are within the number of hours approved in the Service Plan.
9. Make sure that the PASS worker(s)' time sheet(s) reaches the PASS Agency on time which is every two weeks. You must complete the time sheet(s) weekly.
10. Review monthly budget reports of the hours worked and paid from the PASS Agency.
11. Assess and document child's progress toward Service Plan goals and objectives
12. Evaluate the PASS worker's performance in accordance with the Service Plan.
13. Contact your PASS Agency Coordinator when you have questions.
14. Contact your PASS Agency Coordinator if you have concerns so small problems won't become big problems.
15. Maintain a safe and stable working environment in your home.

16. Follow proper reporting procedures (i.e. incidence reports).

Your PASS Agency's Responsibilities to you:

1. Ascertain family preparedness to effectively render consumer-directed PASS services.
2. Provide you with training about the PASS program and modify the training to meet your needs. This includes information about consumer-directed services, Medicaid requirements, recruiting, selecting and managing PASS Workers.
3. Collaborate with you in the development of the Service Plan.
4. Support you in the selection and management of PASS workers. Conduct Background Criminal Investigation (BCI) checks of PASS Workers.
5. Assure proper reporting of hours on timesheets & manage payroll for PASS workers.
6. Talk with you about your satisfaction regarding the quality of services you are receiving and assure that the PASS worker(s) activities are in accordance with the Service Plan.
7. Be available to you to answer questions or provide technical assistance in resolving problems or conflicts.
8. Work with you to develop a corrective action plan if there are difficulties managing your PASS worker(s).
9. Assure compliance with Federal and State employment laws. Monitor compliance with Medicaid Rules and Regulations.
10. Maintain a case record.
11. Assure proper reporting procedures, i.e. incidence reports.

What the PASS Agency will not do:

1. Interview, train or directly supervise your PASS worker(s).
1. Fill out the employment forms package.
2. Find emergency back up direct service workers for you.
3. Write your PASS Service Plan for you.

4. Approve additional hours beyond those authorized in the current Service Plan.
5. Provide your feedback to the PASS worker(s) regarding their job performance.

I understand, accept and agree to the responsibilities listed in this agreement and as delineated in the Service Plan

Family Supervisor(s) Signature

Date

Family Supervisor(s) Signature

Date

PASS Agency Coordinator Signature

Date

PASS Agency Clinical Consultation

Date

* Adapted from "Consumers/Consultant Agreement", Consumers Directed Care Research Project, Florida Agency for Health Care Administration, December 1999

RESOURCE C: DIRECT SERVICE WORKER JOB DESCRIPTION AND CONTRACTUAL AGREEMENT

Job Title: PASS Direct Service Worker

Compensation: The PASS Agency agrees to pay the PASS worker \$_____per hour.

The PASS Agency will withhold and send to federal and state governments all unemployment taxes, social security and federal withholdings. A summary of all payroll withholdings (W2 Form) for the previous calendar year will be sent to you by the PASS Agency by January 31st.

Job Duties of the PASS Worker (taken from Service Plan):

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

Work Schedule

EMPLOYEE START DATE: ____/____/____

The PASS worker's work schedule will be as follows:

Sunday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Monday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Tuesday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Wednesday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Thursday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Friday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

Saturday ____ to ____ A.M.; ____ to ____ P.M.; Total ____ hours
Start time end time Start time end time

TOTAL ____ hrs/week

Responsibilities of the PASS Worker (Please initial):

I _____ agree to report to work on time.

I _____ agree to carry out assigned duties and responsibilities as explained to me
by the Family Supervisor(s) and as written in this agreement and the
Service Plan.

I _____ agree not to do activities unless they are specified in the Individual Service Plan.

I _____ agree to accurately document my hours worked and to file appropriate tax
documents.

I _____ agree to assure proper incident reporting.

I _____ agree to give feedback to the family designee.

I _____ agree to keep progress notes and to give input on the child's progress toward
Service Plan goals and objectives.

I _____ agree to attend and participate in on-going training sponsored by the Family
Support Agency.

I _____ agree to tell the designated family supervisor(s) two weeks in advance of when I
need time off and to obtain written approval. This time will be set by mutual
agreement between the family and me.

I _____ agree to call the designated family supervisor(s) as much ahead of time as
possible if I am sick or unable to get to work on time due to other problems, e.g.
car trouble, etc.

I _____ understand that I am expected to be reliable.

I _____ agree to give the family and the PASS Agency two weeks written
notice if I decide to end my employment.

I have read and understand the job duties expected of me.

Signature of Direct Service Worker

DATE

Signature of Direct Service Worker

DATE

Signature of Designated Family Supervisor(s)

DATE

Signature of PASS Agency Coordinator

DATE

RESOURCE D: CUEING

Using words as cues is a way to tell the child how to do a specific behavior. For example, telling a child to put on their pants before putting on their shoes. These verbal cues can only be used with children who are able to understand the words being used.

Gestures are the use of nonverbal cues to direct the child to do something. Pointing is a common gesture used. In order for gestures to be used as effective cues, the child must have an understanding of what the specific gestures means.

Modeling is a cue in which the desired behavior is actually demonstrated for the child. The use of modeling assumes that the child has reached a certain cognitive level of development that allows him/her to imitate the behavior of others.

Physical prompts as cues involve touches that direct the child's behavior, e.g. touching a child's lips to cue the behavior of closing his/her mouth while chewing.

Hand -over-hand assistance requires the person doing the cueing to place their hands over the child's hands and lead the child through the activity. This requires that the adult be very close to the child and facing in the same direction.

Cues must be faded or gradually tapered off. If this doesn't occur, the child will remain dependent on the cues. Fading or tapering off can be accomplished by pairing less intrusive cues with more intrusive cues and then gradually withdrawing the more intrusive cues, e.g. pairing verbal cues with hand-over-hand assistance and gradually withdrawing the hand-over-hand assistance. Fading can also occur by gradually decreasing the intensity of the cue, e.g. the loudness (intensity) of voice in verbal cueing can progress from loud to soft.

RESOURCE E: ABILITY TO ACCOMPLISH/PERFORM ESSENTIAL ACTIVITIES OF DAILY LIFE AND AGE APPROPRIATE BEHAVIORS

- For newborns and infants (birth to attainment of age 1): Being able to recognize their own body's signals (e.g., hunger, pain, discomfort), and to alert their caregivers of their needs (e.g., by crying). As they mature, their capacity for self-consolation should expand to include rhythmic behaviors (e.g. rocking).
- Older infants and toddlers (age 1 to attainment of age 3): They should be trying to do more things for themselves that increase their sense of independence and competence in their environment. They should be able to console themselves by carrying a favorite blanket with them. Learn how to cooperate with caregivers when they take care of their physical needs but also want to show what they can do; e.g., pointing to the bathroom, pulling off their coat, etc.
- Preschool children (age 3 to attainment of age 6): They should want to take care of many of their physical needs by themselves (e.g. putting on their shoes, getting a snack) and also want to try doing some things that they cannot do fully (e.g. tying their shoes, climbing on a chair to reach something high, taking a bath).
- School-age children (age 6 to attainment of age 12): Increasingly showing independence in most day-to-day activities (e.g., dressing and bathing themselves) although they may still need to be reminded sometimes to do this routinely.
- Adolescents (age 12 to attainment of age 18): They should feel more independent from others and should be increasingly independent in all of their day-to-day activities such as using transportation, handling money and negotiating public places.

*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

RESOURCE F: ABILITY TO MAKE SELF-PRESERVING DECISIONS AGE APPROPRIATE BEHAVIORS

- For Newborns and infants (birth to attainment of age 1): Being able to console themselves (e.g., by sucking on their hand) until help comes. Responding to internal cues that alert them that they need help.
- Older infants and toddlers (age 1 to attainment of age 3): They should be trying to do more things for themselves that increase their sense of independence and competence in their environment. They should be experimenting with their independence by showing some degree of contrariness (e.g., “No, No”) and Identity (e.g., hoarding their toys).
- Preschool children (age 3 to attainment of age 6): Early in this age range, it may be easy for them to agree to do what their caregiver asks. Later, it may be difficult for them because they want to do things their own way or not at all. These changes usually mean that they are more confident about their ideas and what they are able to do. They should also begin to understand how to control behaviors that are not good for them (e.g. crossing the street without an adult).
- School-age children (age 6 to attainment of age 12): They should begin to develop understanding of what is right and wrong, and what is acceptable and unacceptable behavior. They should begin to demonstrate consistent control over their behavior, and should be able to avoid behaviors that are unsafe or otherwise not good for them.
- Adolescents (age 12 to attainment of age 18): They may sometimes experience confusion in the way they feel about how to cope with stress and changes in their environment. However they have emerging confidence in how to appropriately alleviate stress and make self-preserving decisions. Older adolescents should gradually become their own decision makers. They should learn about the various details of managing their own health care.

*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

RESOURCE G: ABILITY TO PARTICIPATE IN SOCIAL ROLES AND SOCIAL SETTINGS AGE APPROPRIATE BEHAVIORS

- For newborns and young infants (birth to attainment of age 1): Respond visually and vocally to caregivers and eventually use gestures and vocalizations to affect others.
- Older infants and toddlers (age 1 to attainment of age 3): Initiate and maintain interactions with adults and play alongside and eventually interact with other children their age.
- Preschool children (age 3 to attainment of age 6): Socialize with children as well as adults and are able to begin to start friendships with other children. They should also be able to use words instead of actions to express themselves, and be better able to share, show affection and offer to help.
- Adolescents (age 12 to attainment of age 18): Initiate and develop friendships and begin to solve conflicts between themselves and their peers or family members or adults outside the family. They should be able to intelligibly express their feelings, ask for assistance in getting their needs met, seek information, describe events and tell stories in all kinds of environments and with all kinds of people.

In assessing a child or adolescent's ability to participate in social roles and social settings in a developmentally appropriate manner, it is important to take a strength-based approach. Examples of areas that might be assessed include:

- Ability to make friends, spend time with them, and engage in group activities
- Make decisions and act independently or to ask for help when either are developmentally appropriate
- The degree to which they sustain attention and use their full abilities to work on tasks and complete them
- Modulate anxiety, depression or hostility when confronted with social situations or task activities that may become frustrating or difficult
- Engage in rather than withdraw from social situations

*Social Security Administration, 20 CFR PART 404 and 416, RIN 0960-AF40, Supplemental Security Income; Determining Disability for a Child Under Age 18

RESOURCE H: CEDARR FAMILY CENTERS

1. About Families

**CEDARR Family Center
203 Concord St. Suite 335
Pawtucket, RI 02860**

401-365-6855

2. Families First CEDARR

**Hasbro Children's Hospital
593 Eddy Street, Room 120
Providence, RI 02903**

401-444-7703

3. Family Solutions CEDARR

**134 Thurbers Avenue, Suite 102
Providence, RI 02905**

401-461-3251

***Note: Additional CEDARR Family Centers may be certified periodically.**

RESOURCE I: DOCUMENTATION GUIDELINES FOR PASS

I. Documentation Requirements

A. PASS Agencies are required to keep all records necessary to fully disclose the nature and extent of the services provided to children receiving PASS. PASS Agencies must furnish to DHS, its agents and/or the Medicaid Fraud Control Unit of the Attorney General's Office such records and any other information regarding payments for claimed or services rendered that may be requested. These guidelines are applicable to all children receiving PASS services authorized by DHS.

The following are the basic principles of documentation. They apply to all types of services.

1. The client record should be complete and legible.
2. The documentation of each client encounter should include or provide reference to:
 - a) The date, time and units of PASS services delivered with a corresponding number of hours that were billed to Medicaid, legible identity/credentials of person providing the PASS services, (i.e. Clinical Consultant, PASS Agency Coordinator and PASS worker)
 - b) All time sheets for the PASS worker must be co-signed by the family

B. Each PASS Agency is responsible for devising a system that documents those services that have been provided. This back-up information is usually contained in the client record, daily log, or both and must be sufficiently detailed to show that a client received a specific number of hours of services on a certain day.

C. All PASS Direct Services Care must be provided in accordance with the PASS Service Plan.

D. Methods of Documentation:

The PASS Agency Clinical Consultant must enter a discharge summary into the client record within 2 weeks after discharge. The Discharge Summary must include:

- a) General observations about the client's condition initially, during interventions and at discharge.
- b) Whether the discharge was planned or unplanned and, if unplanned, the circumstances necessitating the discharge.
- c) Assessment of progress toward the Therapeutic Integration Plan objectives and goals.

- d) Documentation of the summary sent to the CEDARR Family with recommendations for referral to other appropriate program or agency.

II. Monitoring and Quality Assurance

Site visits will be conducted by DHS staff to monitor appropriate use of Medicaid services and compliance with the procedures outlined in this document. During these visits, staff will review the following:

- Client records and PASS Service Plan
- Staff orientation programs and attendance logs
- Agency policy and procedures related to TCYC service provision
- Claims information/documentation
- Staff time sheets
- Complaint log

Providers will be notified of DHS site visits in advance if possible. Unannounced site visits may also be conducted at the discretion of the Department. DHS staff may contact or visit families as part of the oversight and monitoring activities.

In the event of adverse findings of a minor nature, repayment to DHS will be required. In situations where, in the opinion of the Department, significant irregularities in billing or utilization are revealed, providers may be required to do a complete self-audit in addition to making repayments. In either case, technical assistance in developing and implementing a plan of corrective action, where appropriate and applicable, will be offered to the provider.

In addition to monitoring conducted by DHS, providers are subject to periodic fiscal and program audits by the Center for Medicare and Medicaid Studies (CMS).

III. Client Record Guidelines

All PASS services must be provided in accordance with the PASS Service Plan that documents the medical necessity of the services. Plans for clients for whom PASS Agencies are billing Medicaid must conform to the following guidelines:

1. Each client shall have a current written, individualized PASS Services Plan that is based on assessments of the client's strengths and needs that precluded participation in the home or community without the support provided by the PASS Service Plan.
2. Responsibility for the overall supervision of the PASS Service Plan activities must be assigned to an appropriately qualified health care professional.

3. The Service Plan must be thoroughly reviewed at major decision points in each client's course of services including:
 - (a) The time of admission and discharge
 - (b) A major change in the client's condition
 - (c) At least every six months
4. The PASS Service Plan must contain specific goals toward which the client must progress, achieve and/or maintain. These goals must be based on periodic assessments of the prioritized needs of the client and family. These assessments occur through monthly meetings with PASS Agency Coordinator from the PASS Agency and family.

IV. Supplemental Guidelines:

1. Medicaid is, by definition, a medical program, which pays for medical services. The family, a Clinical Consultant and the Direct Service Workers must sign a PASS Service Plan.
2. The diagnosis must clearly be evident in the PASS Service Plan and the diagnosis must be considered as the overall plan is developed
3. The reasons for and types of assistance to facilitate participation and inclusion in the home and community setting should be evident in the plan.
4. Monthly progress notes should reflect a judgment being made by appropriate PASS Agency staff and the family regarding the results of the services rendered, i.e., an assessment of why the interventions are/are not working.

RESOURCE J: ELIGIBILITY CRITERIA FOR PERSONAL ASSISTANCE SERVICE AND SUPPORTS

A child with Special Health Care Needs (CSHCN) requires support on a daily basis for one or more of the following:

- Ability to accomplish activities of daily life
- Ability to make self- preserving decisions
- Ability to participate in social roles and social settings

OR

A child with special Health Care Needs requires support on a less than daily basis as part of a planned transition to greater independence, and/or to prevent circumstances that could lead to more intrusive, restrictive, and/or costly services

Special consideration can also be given to one or more of the following factors:

- Lack of age-appropriate awareness of safety issues so that periodic supervision is required
- Inability to participate in local community programs or activities without support
- Age of either guardian being less than 18 years
- Care responsibilities for other family members with disabilities or health problems
- Availability of only one guardian for care giving.